What is genomic data sharing?

Australian Genomics

Your doctor may recommend **genomic testing** to help diagnose or manage your condition.

Before testing, a health professional will discuss the benefits, risks and possible results with you.

You can then decide whether or not to **consent** to this test:

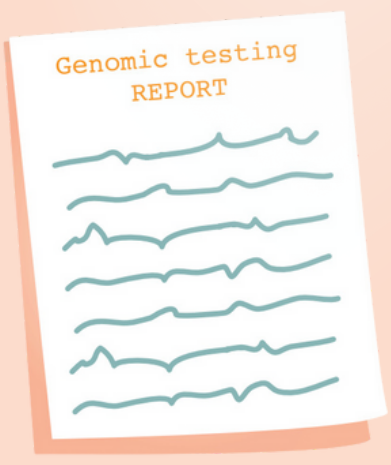
✓ *yes* ✗ *no*

You may be asked to **make a choice** about **sharing** your genomic data:

✓ *yes* ✗ *no*

Genomic testing reads your DNA and produces information called **genomic data.**

Your genomic data is carefully analysed to find genetic changes related to your condition, called **variants.**



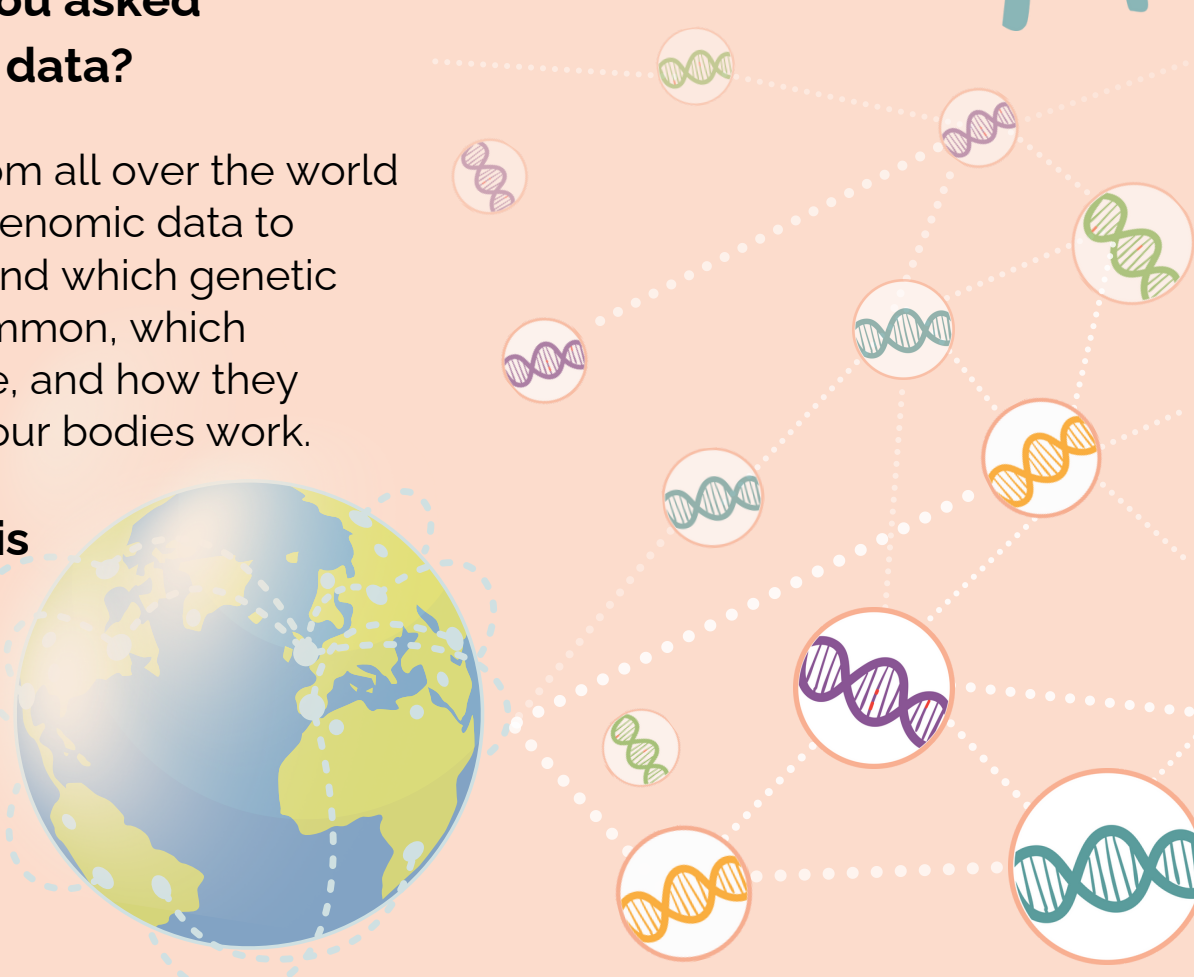
The results are given in a report to your health professional ...

... who can then explain what they mean for you.

So, why are you asked to share your data?

Researchers from all over the world are looking at genomic data to better understand which genetic variants are common, which variants are rare, and how they affect the way our bodies work.

Data sharing is important to this research.



If a researcher is interested in studying your genomic data, they must **apply** for access.

Your data will only be shared if the researchers can prove their work is done **ethically and responsibly.**

If your data is shared, your name and any other personal details are **kept private.**

All researchers have a duty to keep your information **confidential and safe.**

Like all personal data, there is a risk that you could be identified, or a data breach or misuse could occur. Strong Australian Privacy Laws protect your personal information, and there are severe penalties for breaching your privacy.

By sharing your data, you are helping doctors find answers for you, and other people.

Most importantly, remember, the decision to share genomic data is yours.

For more information, visit **genomicsinfo.org.au**

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